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Editorial

Title: Care home data: a COVID-19 wake-up call

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Care home data: a COVID-19 wake-up call

Care home residents are centre-stage in the COVID-19 pandemic, for all the wrong reasons. Home to complex, vulnerable populations, care homes should have been an obvious focus and priority in pandemic planning.[1] Almost half of newly admitted residents in the UK are transferred from hospitals, which creates a resident population with wide ranging needs, spread across 450,000 beds in almost 11,000 homes.[2,3] This is a bed base more than double that of NHS hospitals,[3] but unlike the NHS, a majority of homes are privately owned, with residents responsible for some or all of the costs of their care. Yet as COVID-19 spread across the UK, minutes of the Scientific Advisory Group for Emergencies (Sage) suggest that care homes were discussed only twice in the first five months of 2020.[4]

The COVID-19 pandemic has placed a spotlight on how little is known about this sector, and the lack of easily accessible, aggregated data on the UK care home population. Basic information that could be used to inform service responses, such as the number of residents in homes with and without nursing, hospital admissions and deaths, is difficult to locate.[5] It is not simply lack of data that is the problem; it is the number of different bodies that are collecting information, and the absence of standardization and cross-sector cooperation in how data are collated, shared and used. Care homes collect and use data every day on the needs, health and wellbeing of their residents, and a growing number of homes have sophisticated information systems to monitor medications, support care planning and much more. Health services keep routine records, but data are, rightly, difficult to access. External bodies such as the Care Quality Commission in England and the Care Inspectorate in Scotland collect information for regulation and quality assurance, including data on deaths and disease outbreaks.[6,7] Figures on staffing are collated by Skills for Care and the Scottish Social Services Council.[8] None of these sources were providing timely information in a usable format, and the COVID-19 pandemic triggered rapid responses. Some of the most innovative solutions have emerged at regional level. For example, Health Innovation Manchester has a care data tracker that allows homes to provide real time information about residents to GP practices and hospitals.[9] In north east England, digital collection of national early warning scores and linking of routine health and social care data has accelerated during the pandemic.[10] A capacity tracking app was introduced in England to generate data on bed occupancy and staffing,[11] but it remains the case that there has been no national, systematic approach to care home datasets to exploit their full potential to enhance resident care. The authors of this article are collaborating on a study to address this deficit, and design, develop and implement a minimum dataset for UK care homes.[12] The learning from COVID -19 will directly inform this work and it is our intention that any MDS built

for UK care homes should be a resource to support resident care, and not just a tool for regulation or cost containment.

At the start of the COVID-19 pandemic, longitudinal data on infections and deaths would have allowed real time monitoring, early detection of problems and targeted appropriate intervention. This could have yielded insights into the natural history of Covid-19 in care homes, underpinned evidence-based guidance and identified triggers for service responses. As patients were discharged from hospital to care homes after treatment for COVID-19 infection, data on the health of residents would have been invaluable to develop strategies to protect people at greatest risk and minimize further spread within homes. Such data could also inform the need for bespoke surveillance systems for future pandemic waves in care homes.

At an international level, there has been great interest in care home minimum datasets, but none have been adopted into routine UK care. In the US, nursing homes are federally mandated to contribute to a minimum dataset, and payments are contingent on participation.[13] Related measures, the Resident Assessment Instrument and Dutch National Measurement of Care Problems, are in use in Europe.[14,15] None of these datasets would provide the comprehensive information at the individual resident, care home or organisational level that is needed for health monitoring, and all have faced challenges in implementation. But they are examples of data collection and collation at scale, that the UK can learn from. Timely and accessible data on residents' health, wellbeing and service use could support rational planning and delivery of care that is tailored to residents' needs, something that UK health and social care sectors have often struggled to do. Data are also vital for research, and monitoring of equity in outcomes and access to care. However, workloads are already high in care homes, and it is crucial that data collection is not a burden on staff.

COVID-19 has focused public and political attention on the needs of the care home population, exposing a long-established gap in data intelligence and prioritisation of needs. During a pandemic, information on care home residents' health and care, could make the difference between rapid, effective response from external agencies, and the high infection and death rates that have been hallmark of COVID-19 to date. Political decisions on the funding and organisation of social care over decades have led us to this point.[16] As post-COVID societies question these choices and seek better ways of looking after our older citizens, ensuring that care homes are part of a data system that works to support and protect residents must be a priority.

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